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13. Abstract (Maximum 200 Words) (abstract should contain no proprietary or confidential information) Traditional methods of providing psychosocial interventions for cancer patients are associated with positive patient outcomes but have limited overall impact attributable to low participation rates. The purpose of this project is to implement and evaluate the efficacy of a computer-based psychosocial intervention for women with breast cancer. At the end of the second year of funding, we have continued to implement the SURVIVE intervention, and results from the second year are summarized in this annual report. 243 women have been screened in the UAB breast cancer clinics, and of these 243 women, 109 (45%) have agreed to participate. At the time this analysis was conducted, 69 of these 109 patients had been enrolled and randomized into the trial. Completed time 1 questionnaires have been obtained from 30 women in the control condition and 32 women in the treatment condition. Completed time 2 questionnaires have been obtained from 22 women in the control condition and 20 women in the treatment condition. Recruitment and randomization are expected to be completed this year. Additionally, we have recently submitted two manuscripts related to the project for publication in peer-reviewed journals and anticipate the submission of three additional manuscripts by October 2002.				
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Introduction

The following annual report elaborates progress made towards implementation of an Internet-based psychosocial intervention, ***SURVIVE***, designed to provide information, support, and patient resources to breast cancer patients. The foundations of this intervention were completed as part of the trainee's master's thesis. These foundations include the development of a PERL 5.0 program that manages confidential communications between patients and the trainee's host computer over the Internet, the creation of a patient resource database specific to central Alabama, development of 6 structured intervention modules, and the establishment of a patient referral network. The SURVIVE Web site can be visited at <http://health.psy.uab.edu/survive> using the password "GUEST." A large body of literature indicates that psychosocial support interventions for cancer patients, which provide specific cognitive-behavioral and coping-skills training, are effective in the reduction of cancer pain¹⁻⁵, nausea⁶⁻¹⁰, depression¹¹⁻¹⁵, and anxiety¹⁶⁻²⁰, and may improve indices of survival²¹⁻²⁵. However, few patients take advantage of available support groups²⁶⁻²⁷, and these support groups do not typically provide the structured components demonstrated to result in positive outcomes.²⁷⁻³⁰ In our interactions with newly-diagnosed breast cancer patients, patients also cite logistical constraints (e.g. travel distance or lack of information) as reasons for non-participation. Through the implementation of the currently-funded protocol, SURVIVE, substantial progress has been made in making structured supportive/ informational group services more readily available to breast cancer patients. Documentation of this progress is contained herein.

Psychosocial interventions have been shown to be efficacious in reducing depression, anxiety, pain, and nausea and in improving overall quality of life for cancer patients. However, the public health impact of traditional face-to-face psychosocial interventions for cancer is limited by factors such as geographic availability and low rates of participation. Studies confirm that supportive care programs are in high demand among cancer patients, yet only a small minority of patients are able to access existing services due to required travel time or symptoms associated with cancer treatment or progression of disease. Internet-based psychosocial interventions may be able to increase the public health impact of supportive care services by improving availability and reducing barriers to obtaining these services. The overall goal of this study is to implement and evaluate the effectiveness of an Internet-based intervention (SURVIVE) to increase the availability of structured psychosocial interventions to patients. To meet this goal, we have developed and pilot-tested the SURVIVE intervention among a group of breast cancer patients. On the basis of this pilot-testing, a systematic recruitment has been implemented, and all relevant endpoints are tracked using a database.

In this second year of funding, recruitment and analytic goals have been met. We have randomized a total of 6 cohorts to date: 30 women have been assigned to the control condition, and 32 women have been assigned to the treatment condition. Of these 6 cohorts, all 6 have completed their participation in the conditions to which they were assigned, and follow-up assessments have been received from 22 women in the control condition and 19 women in the treatment condition. Because the 6th cohort only recently received their follow-up assessments by mail, we anticipate receiving an additional 14 time 2 questionnaires by July 1, 2002. Efforts are also underway to obtain time 2 questionnaires from previous participants who have been unresponsive to reminders. These include 5 women in the treatment condition and 1 participant in the control condition. The specific work-related objectives and current accomplishments are detailed below. Tasks 3 and 4 from our original *Statement of Work* described our research aims for the second year of funding.

Task 3. Increased Patient Recruitment at Other Birmingham Hospitals, Months 6-24:

- a. Three honors undergraduate research assistants will participate in recruitment of patients at Medical Center East (collaborating with Kathy Fox, R.N.), Baptist Medical Center (collaborating with Pat Reymann, R.N.), and Brookwood Medical Center (collaborating with Lisa Miller, R.N.)
- b. All patients within 6 months of diagnosis will be asked by collaborating nurses if they can be contacted by telephone to receive information about an Internet-based support and information service.
- c. Research assistants will be trained by the investigator and faculty mentor, Diane Tucker, Ph.D, to make patient contact telephone calls.
- d. Patients who provide verbal consent to be contacted will be telephoned and given information about the services provided through participation in the SURVIVE study.
- e. Collaborating nurses will be provided with information pamphlets about SURVIVE to distribute to all patients. Pamphlets will contain information about contacting the principal investigator.
- f. Research assistants will return calls from interested patients.

Progress Made in Accomplishing Task 3

Regarding task 3a, we were able to secure the verbal support of the three contact nurses mentioned in the statement of work. We provided the participating clinics with informational materials and support to facilitate referrals to the Survive protocol. However, each of the three nurses expressed a preference for conducting recruitment without the assistance of an undergraduate assistant.

The resulting recruitment effort can be described as a failure. No referrals were generated from the three clinics to which we extended outreach efforts.

Accordingly, we made additional outreach efforts to ensure that all breast cancer patients at our home institution, UAB, were being adequately exposed to information about the protocol. Concurrently, 2 additional psychosocial treatment protocols for breast cancer patients, both in the UAB School of Nursing, began recruiting for patients with similar inclusion criteria to our own protocol. Thus, we experienced significant barriers to recruitment. Three undergraduate research assistants were trained by the principal investigator and assisted in the expansion of recruitment efforts to 4 separate clinics within the UAB Kirklin Clinic, allowing us to conduct recruitment in all of the known oncology clinics in which breast cancer patients made up a noteworthy proportion of the patient load. The results of these recruitment efforts are described in detail in Appendix A. Briefly, despite extensive outreach efforts utilizing a number of distinct media, we found that direct patient contact with a study assistant was by far the most effective method for recruiting patients into the Survive protocol. Accordingly, we focused our efforts on this method of recruitment with some measure of success (see below).

109 (45%) of the 243 patients provided with information about the protocol agreed to participate in the trial. Of these, only 63 were randomized into either the control or treatment condition. The remaining patients could not be reached by telephone or failed to return the baseline assessment questionnaires. Recommended changes to the protocol would be to obtain informed consent in the clinic at the time of the initial patient contact and to administer one portion of the lengthy questionnaire at this time. These changes could serve to reduce the number of participants who are lost to telephone contact (perhaps due to busy schedules and fear of evening telemarketing calls) and to lower barriers to participation associated with completing a lengthy questionnaire battery.

Task 4. Implementation of the SURVIVE Supportive Informational Intervention, Months 6-24:

- a. Participants will be randomized to either the SURVIVE intervention or a control group.
- b. Each cohort of 6-10 patients randomized to the SURVIVE intervention will be organized into an E-mail discussion group using PostOffice software.
- c. Patients will be encouraged to send an introductory E-mail to the group describing their diagnosis, treatment, and current primary concerns.
- d. Each week, the investigator will e-mail a new coping module to each enrolled patient, in addition to providing the participant with information to access the coping modules on the World Wide Web through the SURVIVE web site.
- e. Patients will be provided with "homework" questions for each module and encouraged by the investigator to communicate with other patients by E-mail about their personal experience with each module
- f. Patients will be prompted to complete the Web-based questionnaires at each collection point
- g. Participants who complete the 6-week intervention will be encouraged to continue their participation with other group members without formal intervention by the investigator

Progress Made in Accomplishing Task 4

Six cohorts of participants have been recruited and randomized into the Survive protocol. Treatment groups have been successfully organized and enabled to participate in the SURVIVE website. Coping modules have been automated, and each participant receives a new coping module by e-mail approximately every 3 days. Participants have successfully used the SURVIVE website to communicate with one another and to complete coping "homework" questions. Technical difficulties

in using the website have been directed to the principal investigator by individual participants, the vast majority of which are problems with using a password to enter the website. Typically, a password reminder solves the technical difficulty. Time 2 (follow-up) questionnaires have been completed by the majority of participants who have finished the Survive treatment group ($n = 19$). We anticipate that 30 participants in the control condition and 30 participants in the treatment condition will have completed time 2 questionnaire by July 1, 2002 (see Table 1).

Messages and homework exercises sent by participants in the treatment condition have been stored on the principal investigator's host computer for retrieval and analysis, and a master database of time 1 and time 2 questionnaires has been developed using Microsoft Access. No data analysis has been performed using these data. Data analysis will begin in August, 2002. In preparation for analysis of text messages sent to the Survive groups, the principal investigator has worked to develop a "library" of cancer-related words that can be used as an adjunct to Linguistic Inquiry and Word Count text analysis software, thus enhancing our ability to understand the relationship between quality of participation in the treatment group (amount of participation and types of words used by participants) and treatment outcomes (e.g. quality of life, emotional well-being).

Table 1. Questionnaire Batteries Received

	Survive Treatment Group		Control Group	
		Time 2		Time 2
Cohort 1	5	4	5	5
Cohort 2	8	7	8	8
Cohort 3	13	11	13	13
Cohort 4	20	18	20	18
Cohort 5	25	20+	24	22
Cohort 6	32	20+	31	22+

+ indicates that additional questionnaires are expected to be returned in this cell.

Key Research Accomplishments.

- Completed randomization of 6 cohorts of participants
- Data entry complete for all time 1 questionnaires of randomized participants
- Manuscript, entitled "Improving the Effectiveness of Adjuvant Psychological Treatment: The Feasibility of Providing Online Support," submitted to *Psycho-Oncology* in June, 2002
- Manuscript, entitled "Investigation of the Effects of Gender and Preparation on Quality of Communication in Internet Support Groups," submitted to *Computers in Human Behavior* in February, 2002
- Developed word libraries for cancer-related information to facilitate text analysis of messages submitted to Survive treatment groups. Manuscript, in preparation, entitled "Use of the Internet for Information and Support: Disclosure Among Persons with Breast and Prostate Cancer," describes these libraries and will be submitted to *Health Psychology* in July, 2002.
- Collaboration with Carl deMoor and Lorenzo Cohen of the M.D. Anderson Comprehensive Cancer Center Department of Behavioral Sciences in further development of word libraries for cancer-related information, to be applied to messages submitted to Survive treatment groups.
- Principal Investigator's doctoral training is progressing according to the timeline specified by the grant protocol. Specifically:
 - Investigator was granted a Master's degree (M.P.H.) in Health Care Organization and Policy, with a focus on Outcomes Research, by the UAB School of Public Health in December, 2001
 - Investigator completed all coursework and required clinical practicum training hours in February, 2002.
 - Investigator was accepted to complete his predoctoral clinical internship year with Dr. David Wellisch, an expert in the psychological aspects of breast cancer and risk for breast cancer, at the UCLA Neuropsychiatric Institute- the final requirement for his doctoral degree from the UAB Department of Psychology
 - Investigator received the following awards from his department and school:
 - OUTSTANDING GRADUATE STUDENT IN PSYCHOLOGY, 2001-2002
 - OUTSTANDING GRADUATE STUDENT IN MEDICAL PSYCHOLOGY, 2001-2002
 - DEAN'S RESEARCH AWARD, SCHOOL OF SOCIAL AND BEHAVIORAL SCIENCES, 2001-2002

Reportable Outcomes. Ongoing dissemination efforts for DAMD17-00-1-0121.

Published Papers

Owen, J.E.; Klapow, J.C.; Hicken, B.; and Tucker, D. (2001). "Psychosocial interventions for cancer patients: Review of outcomes using a three-dimensional model." *Psycho-Oncology*, 10, 218-230.

Owen, J.E.; Klapow, J.C.; and Casebeer, L. (2000). "Evaluating the relationship between pain presentation and health-related quality of life in outpatients with metastatic or recurrent neoplastic disease." *Quality of Life Research*, 9, 855-863.

Papers in Review

Owen, J.E.; Klapow, J.C., Roth, D.L., Nabell, L., & Tucker, D.T. (In Review). Improving the Effectiveness of Adjuvant Psychological Treatment: The Feasibility of Providing Online Support. Submitted to *Psycho-Oncology*.

Owen, J.E.; Yarbrough, E., Vega, A., & Tucker, D.T. (In Review). Investigation of the Effects of Gender and Preparation on Quality of Communication in Internet Support Groups. Submitted to *Computers in Human Behavior*.

Presentations

Owen, J.E. (October, 2001). "Surfing to Survive." Invited presentation to the UAB Regional Nursing Conference, October 19, 2001.

Richardson, P., **Owen, J.E.**, Oberheu, A.M. (October, 2001). "The UAB Supportive Care Program." Invited presentation to the UAB Regional Nursing Conference, October 18, 2001.

Conclusion

Considerable progress has been made in the second year of this award. Progress from the original Statement of Work is currently on or ahead of schedule for each major task. Recruitment has been lower than was anticipated, but we have obtained a sufficient sample size to commence with initial data analysis. Six cohorts of participants have been recruited into the study and randomized into the protocol. In the next and final year of funding, we hope to continue to collect outcomes data from

current participants and to prepare papers and presentations to meet the data dissemination goals of the study. I anticipate that 3 additional manuscripts will be prepared and submitted to professional journals during this time, and I intend to present the initial results from the project at the upcoming Era of Hope conference and at the 2003 annual meeting of the Society of Behavioral Medicine. No problems have been encountered that could jeopardize our ability to successfully complete the implementation of this trial. We remain excited by the potential reach of this project.

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APPENDIX A: Manuscript submitted to Psycho-Oncology on June 1, 2002

**Improving the Effectiveness of Adjuvant Psychological Treatment:
The Feasibility of Providing Online Support**

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Summary

Many well-designed studies have shown psychosocial treatments for cancer to be efficacious for improving patients' quality of life, but the actual impact of these treatments may be limited by low rates of participation. Web-based treatment formats could improve effectiveness by increasing availability and accessibility. Two phases of a feasibility study are reported in this article. In the first phase, we sought to assess Internet access and perceived interest in online support among 136 women with breast cancer (June-October, 1999). Levels of interest in participating in an online psychosocial treatment were associated with age, outcome expectancy, and barriers to using the Internet but not stage or time since diagnosis. In the second phase, we document accrual rates among several methods of recruitment during a randomized trial (February-December, 2001) and report changes over time in Internet access. Recruitment rates were substantially higher when a study representative was available in clinic to provide information about the treatment than for all other methods of recruitment. Access to the internet increased between 1999 (63%) and 2001 (70%) and varied across age groups. These results suggest that Internet-based psychosocial treatments, with notable limitations, are feasible for increasing the impact of psychosocial care.

Introduction

Adjuvant psychological therapy (APT)¹ for persons with cancer is widely reported to reduce emotional distress, prevalent within oncology populations, and to improve patients' quality of life . However, the impact of APTs has been limited by the poor availability of therapy programs, inaccessibility of existing programs, and lack of professional involvement among health-care administrators and oncology teams. APTs that are designed to address existing limitations, specifically by making therapy programs more widely available, more easily accessible to patients, and more affordable can potentially increase the effectiveness of this class of therapies. Internet-based psychosocial treatments have the potential to address such limitations by expanding the availability and accessibility of APTs to patients with cancer. The specific goals of this study were to 1) examine the feasibility of providing online psychosocial treatment to women with breast cancer by exploring factors associated interest in participation and 2) to describe rates of recruitment success associated with several active and passive recruitment techniques for a clinical trial of an online psychosocial treatment.

Efficacy and Effectiveness of APT

In evaluating the relative merits of psychological treatments, Chambless and Hollon (1998) distinguish between treatment *efficacy*, or the demonstration that a given treatment yields desirable results under controlled conditions, and treatment *effectiveness*, or the ability of the treatment to yield desirable results under the real-world circumstances of actual clinical practice. Arguments for the efficacy of APT for cancer-related distress are well-supported by a number of

¹ The term "adjuvant psychological therapy," after Cunningham (2000), will be used throughout this paper to describe those treatments referred to in previous papers as "psychosocial interventions" (e.g. Meyer & Mark, 1995; Owen, Klapow, Hicken, & Tucker, 2001). The term is considered to be a more precise description of the many treatments that have been provided to cancer populations with the intent of facilitating the psychological processes associated with healing. Use of the operative word "therapy" is also more consistent than "intervention" with existing treatments for cancer and existing treatments for psychosocial distress or disorder among patients without cancer.

reviews and meta-analyses that describe the cumulative results of over 60 studies (Andersen, 1992; Compas, Haaga, Keefe, Leitenberg, & Williams, 1998; Fawzy, Fawzy, Arndt, & Pasnau, 1995; Meyer and Mark, 1995; Sheard & Maguire, 1999; Trijsburg, van Knippenberg, & Rijpma, 1992). Treatment effectiveness, on the other hand, has received considerably less attention. In order for APTs to become practical elements of patient care, they must first be available within or near the cancer centers where patients receive their care and be accessible at times and locations that will allow patients to actually become involved. Since APTs are rarely part of "standard care," they must be actively sought by patients, i.e. patients must perceive themselves as needing additional support. Just as patients are frequently unwilling to take efficacious medications because of complicated dosing schedules or undesirable side-effects, cancer patients are unlikely to participate in APTs that require excessive time commitments or long periods of travel that otherwise distract them from the healing process and their lives outside of cancer.

Interest in psychosocial treatments is high among women with breast cancer (Liang et al., 1990). Women with breast cancer often report tremendous distress and disruptions to lifestyle, including depression, fatigue, cognitive impairments, nausea/ emesis, altered body image, and changes in social support networks, that have a negative impact on quality of life (Stevenson & Coles, 1993; Leedham & Ganz, 1999). To address these difficulties, supportive care and counseling from the medical staff are among the most commonly requested services by patients (Barthow, 1993; Ferrell, Grant, Funk, Otis-Green & Garcia, 1998; Keller, 1998; Liang et al., 1990; Suominen, 1992).

Despite the need for APTs, poor accessibility and availability may be limiting treatment effectiveness. The impact of APTs is illustrated by the participation rates in controlled studies of psychosocial treatment. Within studies targeting breast cancer patients or mixed-cancer samples

with a majority of breast cancer patients, participation rates are highest (70.3% - 100%) for studies involving APTs that are provided as a standard of care, e.g. inpatient nursing support intervention (Maguire, Tait, Brooke, Thomas, & Sellwood, 1980; see also Maguire, Brooke, Tait, Thomas & Sellwood, 1983; McArdle, George, McArdle, Smith, Moodie, Mark Hughson et al., 1996; Wieder, Schwarzfeld, Fromewick, & Holland, 1978) or relaxation training during chemotherapy or radiation (Bridge, Benson, Pietroni, & Priest, 1988; Elisabet Palsson & Norberg, 1995; Maunsell, Brisson, Deschenes, & Frasure-Smith, 1996; Vachon, Lyall, Rogers, Cochrane, & Freeman, 1982; Walker, Walker, Ogston, Heys, Ah-See, Miller, et al., 1999). For studies in which participation required time or travel beyond what would be required for standard medical treatment, participation rates are considerably lower (15.5% - 82%, median = 35.1%, Cunningham, Edmonds, Jenkins, Pollack, Lockwood, & Warr, 1998; Donnelly, Kornblith, Fleishman, Zuckerman, Raptis, Hudis et al., 2000; Edgar, Rosberger, & Nowlis, 1992; Fukui, Kugaya, Kamiya, Koike, Okamura, Nakanishi et al., 2001; Goodwin, Leszcz, Quirt, Koopmans, Arnold, Dohan et al., 2000; see also Goodwin, Leszcz, Ennis, Koomans, Vincent, Guther et al., 2001; Moorey, Greer, Bliss & Law, 1998; Rustoen, Wiklund, Hanestad, & Moum, 1998; Shrock, Palmer, & Taylor, 1999; Youssef, 1984). In conceptualizing treatment effectiveness, a median participation rate of 35.1% is likely to be an overestimate. Recruitment success rates for the studies mentioned above are described, in most cases, for samples already meeting inclusion criteria for the study (e.g. patients available for follow-up or living within a one-hour radius of the treatment facility, see Goodwin et al., 2000 for an exception). Only a handful of studies reported recruitment success rates among consecutively approached patients (Bridge et al., 1988; McArdle et al., 1996; Walker et al., 1999).

Because the *availability* of APT for cancer has been largely limited to ongoing clinical trials associated with academic medical centers in select cancer centers, treatment effectiveness is further limited in scope. Community-based support groups, such as those offered through the American Cancer Society (Coluzzi, Grant, Doroshow, Rhiner, Ferrell, & Rivera, 1995), are generally available to patients in metropolitan areas, but only a small proportion of patients take advantage of these services. Further, studies examining the treatment efficacy for community-based support groups have not to this point demonstrated significant improvement in patient outcomes (Andersen, 1992; Gruber, Hersh, Hall, Waletzky, Kunz, Carpenter et al., 1993; Jacobs, Ross, Walker & Stockdale, 1983; Telch & Telch, 1986).

Improving Effectiveness by Using Internet-Based APT

As a compliment to existing psychosocial treatments, internet-based APT could address some of the reasons for the limited effectiveness of APT by making these treatments more available and accessible to patients with cancer. A small, emerging body of evidence suggests that some barriers to participation in APT can be overcome by the use of internet-based media. Locating and participating in psychosocial services, particularly when services are not provided in connection with the health-care team, is one such obstacle to patient participation. Fatigue is experienced by approximately 80% of cancer patients during and after treatment and results in substantial lifestyle disruptions (Vogelzang, Breitbart, Cella, Curt, Groopman, Horning et al., 1997; Woo, Dibble, Piper, Keating & Weiss, 1998). Internet-based APT obviates the need for a physical meeting place and the need for participants to travel from their homes (Winzelberg, 1997; Finn, 1995; Weinberg, Shmale, Uken & Wessel, 1995). Internet-based APT may be more accessible to patients who live at great distance from the clinic (e.g. in small, rural areas where support services are unavailable), who do not have a convenient means of transportation, or who

are too physically debilitated or fatigued to travel. Additionally, users of online groups are able to access the group at any time of day or night (Weinberg, Schmale, Uken & Wessel, 1996; Winzelberg, 1997; Finn, 1995; Weinberg et al., 1995). Winzelberg reported that 66% of the messages posted to an online group were sent between 6pm and 7am (1997). This allows participation by patients whose employment requirements or household responsibilities prevent participation in face-to-face groups. Initial reports suggest that women with breast cancer find internet-based discussion groups and bulletin boards to be helpful (Gustafson, Hawkins, Boberg, Pingree, Serlin, Graziano et al., 1999; McTavish, Gustafson, Owens, Hawkins, Pingree, Wise et al., 1994; Weinberg et al., 1995; Weinberg, Uken, Schmale, & Adamek, 1995; Owens & Robbins, 1996), yet rates of Internet-access, familiarity with the use of computers, and perceived benefits of online psychosocial services have not been evaluated within a general population of women with breast cancer. A detailed characterization of the population interested in Internet-based APT is a prerequisite to assessing the potential impact of providing psychosocial interventions over the Web.

Improving Effectiveness by Understanding Factors Associated with Participation in APT

An essential aspect of increasing the effectiveness of APT is to better understand the factors associated with participation in psychosocial care. Factors associated with participation in APT may be a function of perceived *interest* (e.g. cancer stage, time since diagnosis, existing social support, etc.), *availability* (e.g. existence and awareness of community-based support groups, professionally-lead therapy groups, or individual treatment options), or *accessibility* (e.g. the distance a participant would need to travel to a meeting place, time constraints associated with lifestyle, encouragement by friends or family, etc). Previous studies suggest that factors predicting participation in face-to-face APT include recent surgery, age (highest among women

aged 50-65, Fukui et al., 2001) and a desire to receive and give emotional support and information (Stevenson & Coles, 1993). Other studies suggest that refusal to participate in a psychosocial treatment is associated with progressive disease and lack of encouragement from family members (Gustafson, Wise, McTavish, Taylor, Wolberg, Stewart et al., 1993); hesitation to commit to regular group meetings (Cunningham et al., 1998); busy home and work schedules (Fukui et al., 2001); and an already adequate level of social support (Plass & Koch, 2001). However, there have been few systematic studies of participation in APT and none that have examined potential factors associated with the use of internet-based psychosocial treatments (Andersen, 1992).

Improving Effectiveness by Understanding Patient Outreach Efforts

Almost nothing is known about which recruitment methods are most effective for making patients aware of psychosocial services and reducing barriers to involvement. In many oncology centers, brochures are the primary mechanism by which patients are informed about the availability of APTs (e.g. Plass & Koch, 2001). Patients are often expected to seek psychosocial care independently, without referral or recommendation from their health-care team (Eakin & Strycker, 2001). Within clinical trials of APT, a number of active and passive recruitment mechanisms have been employed, including use of advertisements or brochures, announcements in the media, direct mailings to patients, referrals for psychiatric or psychological care, and direct patient contact. Goodwin et al. (2000) provide the most extensive description of recruitment methods to date but sources of referrals were not recorded for participants, therefore relative success rates could not be determined. In other types of clinical trials, recruitment methods have been explored in greater detail (Siminoff, Zhang, Colabianchi, Sturm & Shen, 2000; Tworoger, Yasui, Ulrich, Nakamura, LaCroix, Johnston et al., 2002). The present study documented the

referral source for all participants in an online psychosocial treatment group so that the relative efficacy of each could be determined.

Goals of the Present Study

The goals of the present study were 1) to evaluate the relationship between stage, time since diagnosis, age and interest in an internet-based APT; 2) to evaluate the accessibility of APT by examining rates of Internet access among women with breast cancer and perceived benefits and barriers to participation in an internet-based APT; and 3) to evaluate the efficiency of several different recruitment strategies in making a clinical trial of an internet-based APT available to participants. Because little is known about rates of Internet access and familiarity with computers among women with breast cancer, we sought to characterize computer literacy in this population and to identify factors that could increase the efficiency of recruitment into a larger, ongoing clinical trial of a structured, online psychosocial intervention. To better understand factors contributing to interest in participation, we also investigated potential mediating effects associated with interest. Consistent with previous research on social cognitive theory, we hypothesized that the effects of barriers and social support on interest would be mediated by self-efficacy and outcome expectancy (Bandura, 1997). We further hypothesized that social support would directly predict interest in an internet-based therapy.

Methods

Participants

Women diagnosed with breast cancer were identified consecutively from appointments made in the Department of Hematology/Oncology at the University of Alabama at Birmingham Comprehensive Cancer Center. Of all patients seeking care at the UAB CCC, 10.6% have been diagnosed with breast cancer. Approximately 24% of the CCC's patients are from minority

populations, 50% reside outside the 8-county region surrounding the CCC, and 10% travel from other states or countries for treatment. Patients with histologically confirmed cancer of the breast were eligible for participation regardless of time since diagnosis.

During Phase I, 192 eligible patients were approached between June and October 1999, and 136 agreed to participate and complete the questionnaires described below (70.8% participation rate). In Phase II of the study, performed after the completion of Phase I, 243 consecutive patients were recruited by direct contact with a study assistant for participation in a randomized clinical trial of an internet-based APT between April 2001 and April 2002. Additionally, 68 patients who self-referred to the clinical trial were included in the analyses of recruitment mechanisms. None of the patients in the second phase were asked to complete questionnaires.

Procedure

During phase I, medical charts of patients scheduled to receive consultation for breast cancer were examined by a referring physician, and patient age, race, and clinical stage were recorded. As eligible patients checked in for scheduled appointments, a study assistant provided the patient with a brief description of the study, stating that the oncologist (L. Nabell) sought to better understand the needs of her patients. After receiving verbal consent, participants completed the brief questionnaire while waiting to see the oncologist. Upon completion of the questionnaires, participants were invited to participate in a pilot study for an internet-based APT.

Phase II employed a number of recruitment mechanisms to enroll women with breast cancer into a randomized clinical trial of an internet-based APT. Direct patient contact required a study assistant to provide a brief description of the clinical trial, which involved 12 weeks of participation in an internet-based APT for small groups of women with breast cancer, to patients

visiting one of 3 medical oncology clinics at the UAB Comprehensive Cancer Center. When patients declined to participate, the study assistant recorded the reason given by the patient (e.g. lack of access to the Internet). Patients who agreed to participate were later contacted by telephone and enrolled in the clinical trial. No questionnaires were administered during this phase of the study.

Additional recruitment efforts included 1) attending nursing in-service education programs to enable oncology nurses to refer patients, 2) placing full-color posters with business-reply postcards in each of 13 patient examination rooms in Hematology/ Oncology, 3) including business-reply postcards and brochures in American Cancer Society Reach to Recovery materials distributed by volunteers to newly diagnosed patients, 4) submitting a press release to facilitate outreach efforts through local and national print and television media, 5) contacting major oncology-related websites to request a link to the website for our internet-based APT, and 6) conducting physician education programs in 4 Birmingham-area hospitals. A detailed log of patient referrals was kept for each recruitment source throughout the recruitment period.

Measures

Social support was assessed using the Medical Outcomes Study Social Support Survey, which consists of 19 items based on a 5-point Likert-type scale (Sherbourne & Stewart, 1991). The MOS Social Support Survey is characterized by high internal consistency ($\alpha=0.97$) and convergent validity for correlations with loneliness, family functioning, and psychological well-being. In addition to an overall score, four subscale scores can be generated from this instrument: tangible support, affectionate support, positive social interaction, and emotional/informational support.

Two brief questionnaires were developed for the purposes of this study. The Computer Access Survey consisted of 8 dichotomously scored items regarding the participants' access to computers, e-mail, the World Wide Web, and online sources of cancer information and support. The Computer Attitudes Survey was designed to sample constructs derived from the Health Belief Model (Rosenstock, Strecher, & Becker, 1988) and Social Cognitive Theory (Bandura, 1986) that were hypothesized to predict intentions to participate in an internet-based APT. These constructs included perceived benefits/outcome expectancy of face-to-face support services (3 items, $\alpha = 0.77$), perceived benefits/ outcome expectancy of computer support services (3 items, $\alpha = 0.89$), perceived barriers to computer support services (2 items, $\alpha = 0.19$), and self-efficacy for computer use (3 items, $\alpha = 0.98$). Because the two items representing barriers to the use of computer support services (perceived difficulty sharing feelings over a computer, preference for face-to-face support) exhibited low internal consistency, these 2 items were entered separately in all models involving this construct. Each item of the Computer Attitudes Survey was measured using a 7-point Likert scale.

Additionally, participants were asked to self-report their annual household income, education, current use of a support group, and treatment status. Interest in participating in the internet-based APT was measured using a single, 7-point Likert scale ranging from "not at all interested" to "extremely interested." Participants who were willing to take part in the pilot study of the internet-based APT were asked to provide their name and phone number for a follow-up contact.

Results

Participants

The 136 phase I participants completing questionnaires did not differ from the 56 non-participants in age (mean = 53.9 years, $t(176) = 0.2$, $p = 0.84$), ethnicity (84% White, 16% African-American, $\chi^2(1) = 2.38$, $p = 0.12$), or clinical stage (28.7% stage I, 40.1% stage II, 11.5% stage III, 19.7% stage IV, $\chi^2(3) = 3.35$, $p = 0.34$). At the time of the assessment, 38% of participants had undergone lumpectomy, 59% had undergone mastectomy, 48% had been treated with radiation, and 66% had been treated with at least one regimen of chemotherapy. Seventy-seven percent of the participants were in long-term follow-up and were not currently receiving radiation or chemotherapy, although many of the participants were taking tamoxifen for prevention of recurrence. Average length of education was 14 years, and median annual household income was \$45,000. Mean time since initial diagnosis of breast cancer was 29 months, and participants traveled an average of 75 miles from their home to the clinic one-way. Demographic and treatment data for the 243 participants in phase II were not recorded.

Patient Characteristics and Interest in Internet-Based APT: Phase I

In order to test the relationship between patient characteristics that could be quickly ascertained by chart review and interest in participation in an internet-based APT, simple correlations between interest and distance from clinic, age, education, income, and time since diagnosis were calculated. Analysis of variance (ANOVA) was used to evaluate the relationship between clinical stage, a categorical variable, and interest in participating, a continuous variable. Interest in participating was not statistically correlated with distance from clinic, education, income, or time since diagnosis but was significantly associated with age, $r = -0.29$, $p = 0.002$. Women below age 45 exhibited the highest level of interest (mean = 5.07, max = 7), with interest decreasing as age increased: women age 46-55, mean = 3.96; women age 56-65, mean = 3.85;

women age 66-75, mean = 2.92; women age 75+, mean = 2.5. Clinical stage was not significantly associated with interest in participation.

Psychological Characteristics and Interest in Internet-Based APT: Phase I

Correlations between theoretical psychological constructs (outcome expectancy/ benefits of internet-based APT, barriers to participation in internet-based APT, self-efficacy for computer use, and existing social support) and interest in participation were obtained (see Table 1).

Multiple regression was employed to test the relationship between these variables as a set and interest in participation, and the combined set of variables significantly predicted interest, $R^2 = 0.51$, $p < 0.0001$.

Structural equation modeling methods were employed using maximum likelihood estimates generated by SAS (v. 8.0) Proc CALIS to examine the predictive effects of outcome expectancy, barriers, self-efficacy, and social support to interest in participation in the context of a mediation model. Forty-one subjects were not included in this analysis due to incomplete data on one or more of the variables tested. Because the Proc CALIS procedure used listwise deletion, this analysis was repeated using pairwise deletion, and the pattern of results was unchanged. The hypothesized model did not provide an adequate fit to the data, $\chi^2 (10, n = 94) = 27.9$, $p = 0.002$. Using the Lagrange multiplier test, post hoc modifications were performed and tested using chi-square difference tests to develop a model with better fit to the observed data (Figure 1). The final model was obtained by adding a pathway from social support to outcome expectancy, $\chi^2_{\text{diff}} (1) = 4.7$, $p < 0.05$, and adding a covariance pathway between self-efficacy and outcome expectancy, $\chi^2_{\text{diff}} (1) = 8.5$, $p < 0.05$. Overall, the fit indices indicated that the final model provided adequate fit to the observed data (GFI = 0.95, CFI = 0.93, NFI = 0.88).

Internet Access Among Women with Breast Cancer: Phase I

Levels of access to the Internet for and computer services for phase I participants are shown in Table 2. Levels of Internet access showed considerable variations across age groups. 90% of women aged 45 or below reported having access to the Internet compared with 63.3% of women aged 46-55, 65.6% of women aged 56-65, 28.6% of women aged 66-75, and 0% of women over the age of 75. In the phase II sample from 2001, access to the Internet increased to 69.1% from the 62.5% level observed for phase I.

Outcome Expectancies for Face-to-Face and Internet-Based APT: Phase I

Among phase I participants, 29.6% reported more positive outcome expectancies of internet-based APT than for face-to-face APT, 34.1% reported more positive outcome expectancies for face-to-face APT, and 36.3% reported outcome expectancies that did not differ between internet and face-to-face APT. Relative outcome expectancies for face-to-face or internet-based APT were not associated with access to the Internet, $\chi^2(2) = 1.56$, $p = 0.46$.

Success of Recruitment Strategies: Phase II

In phase II of the study, recruitment success for each recruitment strategy was estimated by several methods: the raw number of patients who indicated a desire to participate in the clinical trial of an internet-based APT, the number of patients who were actually enrolled into the trial, and the cost per patient enrolled. Recruitment success associated with each recruitment strategy is displayed in Figure 2. Average costs associated with each strategy were calculated as a function of direct expenses for materials and the salary time of the predoctoral investigator who coordinated the recruitment effort (avg. \$6.97/hour). The costs per patient enrolled into the clinical trial are as follows: \$0 for referrals from patients already in the study, \$1.27 for clinic posters with business-reply postcards, \$1.39 for national print media reports and articles, \$3.10 for local print media reports and articles, \$6.97 for efforts to advertise the study on cancer-

related web sites, \$22.63 for direct patient contact in local clinics, \$34.85 for local television and radio reports, and \$139.40 for outreach to nursing organizations and area hospitals. Across recruitment strategies, 66.3% of the patients who asked to be involved in the trial were later enrolled as participants in the trial. The remaining 34.7% either could not be contacted by study staff or refused participation after taking part in the informed consent process.

Among the 243 patients approached directly by a research assistant, 109 (44.9%) asked to be involved in the clinical trial. At the time this analysis was conducted, 69 of these 109 patients had been enrolled and randomized into the trial. The remaining 134 patients declined to enroll in the trial for a variety of stated reasons, including lack of access to a computer or the Internet ($n = 47$), lack of familiarity with computers or the Internet ($n = 20$), a desire for time to look over the study materials ($n = 19$), perception that breast cancer was “behind” them ($n = 12$), adequate existing support ($n = 10$), being “too busy” ($n = 8$), being in a support group already ($n = 3$), fear of interacting with others who might be depressed or sick ($n = 1$) or feeling too sick to be involved ($n = 1$). Thirteen patients did not provide a reason for declining to enroll.

Discussion

Internet-based psychological therapy is a feasible compliment to face-to-face psychosocial care. An increasing percentage of women with breast cancer, nearly 70% in our most recent sample, has access to the Internet, and nearly 66% report that internet-based APT is equally or more likely to result in improved physical and mental health than face-to-face therapy. When made aware of the availability of participating in internet-based APT, 45% asked to become a member of a small therapy group. Among patients who had access to the Internet and declined to participate, few cited logistical constraints as a reason for not being involved. Thus,

by making an Internet-based APT available, previous barriers to participation can be overcome, and the overall impact of adjuvant psychological therapy could be enhanced.

Patient characteristics associated with interest in being involved in an internet-based APT provide insight into how such services can be provided. First, it should be noted that the demographic profile of our phase I sample differed slightly from recent census data in the state of Alabama. Data from the 2000 census show that median educational attainment in the state was a high school diploma, and median annual household income was \$34,135 (U.S. Census Bureau, 2002). As is true for the general patient mix at the cancer center where the study was conducted, participants were slightly better educated and wealthier than the average citizen of the state. Second, interest was modestly associated with age. A majority of women under 65 had access to the Internet, and they express higher levels of interest in internet-based psychosocial services. Younger women are also more likely to have barriers to participation associated with lifestyle constraints (e.g. work responsibilities, caring for dependent children or older adults), making this group especially likely to take advantage of internet-based services. Other cancer populations with lower mean age at diagnosis may also be expected to benefit from internet-based services (e.g. Hodgkin's, acute lymphocytic leukemia, and cancers of the brain, ovary, testis, or thyroid). Third, neither stage nor time since diagnosis was related to interest. These results suggest that the need for adjuvant psychosocial care is not attenuated with time.

Among the psychological factors hypothesized to predict interest in participation, outcome expectancies mediated the effects of social support, preference for face-to-face psychosocial care, and perceived difficulty sharing feelings on the Internet. Helgeson and colleagues (2001) have previously reported that patients with adequate social support do not benefit from participation in APT, yet they may serve a valuable role in sharing support with

those who are less fortunate. In this study, women interested in participating in internet-based APT frequently reported to research assistants that they wished to be involved in order to help others without sufficient support, and providing such support may serve as a coping mechanism for these women. Patient outreach efforts designed to address outcome expectancies and perceived barriers to participating in internet-based therapy may serve to increase interest in participation. Familiarity with computers is a significant barrier to involvement in these services, particularly for elderly patients. Given that personal computers first became readily available to the general public within the last 20 years or so, self-efficacy for computer use would be expected to be related to age and should also change rapidly over the next several years as cohorts who are more familiar with computers reach ages that are associated with higher incidence rates of cancer.

The manner in which the availability of APT is communicated to cancer patients plays an important role in actual participation. In the present study, women who were approached face-to-face were more likely to indicate interest and to actually enroll in the trial. Although placing full-color posters with business-reply postcards in patient exam rooms resulted in nearly 20 interested patients and 11 who enrolled in the trial, over 500 postcards were taken, but not returned, by patients. Thus, the overall yield to the trial was approximately 1 enrolled participant for every 50 postcards distributed. Similarly, media exposure resulted in relatively few enrollments and even the high profile of a national magazine resulted in only 15 enrolled participants. Paid advertising in this magazine would have cost over \$10,000 and might not have been effective for recruitment purposes. Clinicians must also cede control of how the treatment program is described and presented to the media sources, which in some cases can limit recruitment success. For example, the local television story that reported our work aired only

during the late night news program and did not provide a web site address for interested patients to contact. Direct patient contact was more expensive than other forms of recruitment, but it offers a number of clear advantages. Interacting individually with patients, in the private setting of an exam room, can help communicate to patients that cancer-related distress is common for persons with cancer. In so doing, patients may attach less stigma to the notion of being involved in a psychological therapy or support group. Direct patient contact also minimizes the amount of energy a patient must expend to become involved, effectively reducing the number of barriers to participation. However, in order for face-to-face recruitment to be effective rather than simply efficacious, it must become a standard of care in treatment centers where APT is available. Otherwise, participation in APT will be limited only to well-funded clinical trials in which a staff member can be paid to assist with recruitment. Further, because physicians are often unaware that patients are experiencing distress and seek supportive services such as those provided by psychological therapies (Burstein et al., 1999; Cull, Stewart, & Altman, 1995), functional collaborations with referring physicians and nursing staff are essential to both provide patients with information about available services and to encourage them to take advantage of these programs (Burton & Watson, 1999).

Our results suggest that few women with breast cancer acknowledge seeking supportive services to obtain support for themselves, but rather they express motivation to seek these services as a source of information, to alleviate depression or anxiety about cancer, to cope with side-effects of treatment, and to give support to others (Burstein et al., 1999; Stevenson & Coles, 1993). For researchers and providers of psychosocial interventions, a needs-matching strategy, in which individual patient needs are matched with distinct types of APT, may be necessary to increase participation rates and to maximize the benefits of supportive services. In the context of

interdisciplinary care, tailored educational strategies aimed at increasing perceived benefits and reducing perceived barriers to these services could greatly increase participation rates for psychosocial intervention studies. At a minimum, a simple and veridical endorsement from the oncologist could serve as a positive and highly effective intervention in itself to increase perceived benefit and consequent likelihood of participation.

Importantly, the efficacy of internet-based APT for improving quality of life in breast cancer patients has not yet been demonstrated in randomized trials. One published report of an internet-based APT for breast cancer patients younger than 60 has shown significantly improved social support (Gustafson, Hawkins, Pingree, McTavish, Arora, Mendenhall et al., 2001). A notable number of breast cancer patients are already turning to Internet discussion groups and chat rooms to seek support and information (Sharf, 1997). Researchers have been limited to observational studies in evaluating the effect of participation in these kinds of widely-available support networks (Epstein & Klinkenberg, 2001; Klemm, Hurst, Dearholt, & Trone, 1999). Studies that are able to compare communication and outcomes associated with discussion groups and structured therapy groups on the Internet would be valuable to the advancement of this field.

The availability of internet-based APT will expand the arsenal of treatment options available to psycho-oncologists and oncology teams, particularly as efforts to increase access to internet technologies in hospitals and clinics continue to grow (Eng, Maxfield, Patrick, Deering, Ratzan, & Gustafson, 1998). Psychosocial services (e.g. support groups, individual counseling, structured group interventions, pastoral care, information/resource support), largely neglected or under-funded in traditional health-care environments, may become more accessible to patients and less expensive for providers when offered online. Access to the Internet, and internet-based

adjuvant psychological therapy in particular, offers the potential to empower patients to enhance their ability to cope with their disease and to participate more actively in their recovery.

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Author Note

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Table 1. Correlations among psychological variables and regression on interest in participating in internet-based APT.

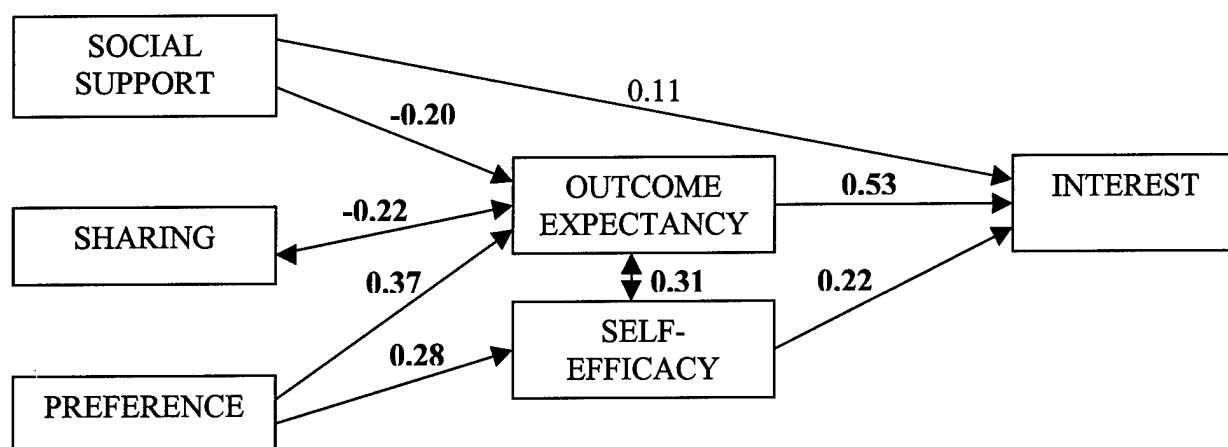
Variable	Interest (DV)	1.	2.	3.	4.	5.
1. Social Support	-0.136	1.00				
2. Outcome Expectancy	0.670 ***	-0.171	1.00			
3. Self-Efficacy	0.456 ***	0.020	0.372 ***	1.00		
4. Difficult to share feelings using a computer	-0.293 **	-0.071	-0.303 **	-0.184	1.00	
5. More comfortable in face-to-face group than computer	0.487 ***	-0.099	0.477 ***	0.271 **	-0.104	1.00
Means	4.11	87.1	4.19	5.05	3.56	3.81
(Range)	(1-7)	(20.3- 99.9)	(1-7)	(1-7)	(1-7)	(1-7)
Standard deviation	2.28	16.6	2.02	2.29	2.11	1.83

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Table 2. Access to computers and the Internet among women with breast cancer.

Item	% of Phase I Participants (n = 136)
Have ever used a computer.	73.3%
Own or lease a home computer.	55.0%
Have access to a computer outside of home.	69.2%
Have access to the Internet.	62.5%
Have own e-mail account.	54.7%
Have interacted with other cancer patients using the Internet.	6.9%
<u>Have used the Internet as a source of cancer information.</u>	<u>38.9%</u>

Figure 1. Path model and maximum likelihood estimates for predicting interest in participation in an internet-based psychosocial treatment.



* Paths significant at the $p < 0.05$ level are shown in bold print; SOCIAL SUPPORT = total social support, SELF-EFFICACY = self-efficacy for computer use, SHARING = difficulty sharing emotions via e-mail, PREFERENCE = preference for face-to-face support over internet-based APT, reverse-scored, OUTCOME EXPECTANCY = likelihood of physical or emotional benefit from participation in an internet-based APT, INTEREST = interest in participating in internet-based APT.

Figure 2. Number of patients recruited and enrolled into a clinical trial of internet-based APT by recruitment strategy.

